People with Exceptionally Complex Needs Project (PECN)

Dr David Worth (Principal Research Officer)
Education & Health Committee
Inquiry into the Adequacy and Appropriateness of Prevention
& Treatment Services for Alcohol and Illicit Drug Problems
Level 1, 11 Harvest Terrace
WEST PERTH WA 6005

Dear Dr Worth

Please find attached a submission to the Western Australian Parliamentary Education and Health Committee Inquiry into the Adequacy and Appropriateness of Prevention and Treatment Services for Alcohol and Illicit Drug Problems on behalf of the Inter-Agency Executive Committee for the People with Exceptionally Complex Needs Project (PECN).

The PECN Inter-Agency Executive Committee would appreciate the opportunity to address the Committee in person in regard to the particular needs of this challenging group of people. The PECN Coordinator, Amanda Perlinski is available to respond to any questions or to provide evidence to the committee if requested. Amanda Perlinksi can be contacted on 9426 9675, via email at amanda.perlinski@dsc.wa.gov.au or at The Disability Services Commission, PO Box 441, West Perth 6872.

Yours Sincerely

DR STEVE PATCHETT
CHAIR
Inter-agency Executive Committee
People with Exceptionally Complex Needs Project

30TH July 2009

Enc: as above

Health and Education Committee Legislative Assembly (Standing Committee) Inquiry into the Adequacy and Appropriateness of Prevention and Treatment Services for Alcohol and Illicit Drug Problems in Western Australia

Submission on Behalf of the People with Exceptionally Complex Needs (PECN) Inter-Agency Executive Committee

The People with Exceptionally Complex Needs (PECN) initiative is a pilot project which provides co-ordinated, whole-of-government service delivery response to improve the well-being and quality of life of individuals with exceptionally complex needs utilising existing resources of the partner agencies. Five or six individuals are assisted at a time during the course of the pilot.

The target group for the project is adults (18 years of age and older) who have two or more of the following:

- a mental illness; or
- an acquired brain injury; or
- an intellectual disability; or
- a significant substance use problem; **and**
- pose a significant risk of harm to self or others; **and**
- require intensive support, would benefit from receiving co-ordinated services; **and**
- for whom the existing system is not working as well as it should.

The PECN target group represents a very small yet highly resource intensive population. People in the PECN target group tend to require very high levels of support in multiple program areas, and often represent a significant risk to themselves and the community.

An evaluation of the project will begin later this year. While evaluation findings are not yet available, a number of potential service gaps have already been identified during the screening of potential participants and development of support plans by inter-agency teams. This includes a lack of appropriate prevention and treatment services for people with acquired brain injury or intellectual disability, often co-morbid with mental illness, which is the focus of this submission.

This submission seeks to respond to Term of Reference 1(b) for the inquiry relating to the "evidence base, adequacy, accessibility and appropriateness of the broad range of services for treatment and support of people with alcohol and drug problems and their families, and the most appropriate ways to ensure integrated care" with specific reference to drug and alcohol treatment services for people with these exceptionally complex needs.

The screening of potential participants for the PECN pilot project, and the development of support plans by inter-agency teams for PECN participants,

has identified that current treatment services in Western Australia are ineffective for this group.

The purpose of this submission is to describe the experiences of people with cognitive and/or intellectual disabilities together with mental health problems in mainstream treatment services and to identify the principles of good practice that would guide an effective treatment response for this group.

Adequacy, Accessibility & Appropriateness of Current Treatment Services for People with Intellectual, Cognitive Disabilities and Mental Health Problems.

While people with mental health problems are not uncommon within drug and alcohol treatment services there is a perception that people with intellectual disabilities, in particular, rarely use drugs and alcohol. However, research and anecdotal experiences by key stakeholders indicate that the potential impacts of drug and/or alcohol use are exacerbated by co-morbid cognitive and/or intellectual disability.[1] People with intellectual disability also have a higher rate of co-morbid mental health problems which are also often exacerbated by substance use. This group have a poorer prognosis and increased treatment complexity. People with disabilities also have more complex physical health needs that are considerably worsened by alcohol use including epilepsy, cardiovascular, respiratory tract and gastrointestinal problems. Their generally poor functioning in areas such as decision making is also further impaired by both alcohol and drug use.

Most treatment programmes currently available in Western Australia to prevent and treat alcohol and drug problems are based on cognitive, psychodynamic approaches. These approaches are not effective for people with intellectual or cognitive disabilities in particular as they require a degree of abstract reasoning that most people with intellectual or cognitive disabilities do not have due to the nature of their disability. People with intellectual or cognitive disabilities require a behaviourally based approach, which is not currently available in Western Australia.

While some people with intellectual or cognitive disability with less serious levels of addiction appear to benefit to some extent from community based counselling services, these counselling services are often not accessible to people with intellectual or cognitive disabilities. People with intellectual or cognitive disabilities require materials to be presented in a more tangible way than those without such disabilities, and individual counsellors often do not have the personal skills and interests to provide counselling in an appropriate format.

People with cognitive, intellectual and psychiatric disabilities also have no access to adequate and appropriate residential rehabilitation options.

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[1] Degenhardt, Louisa (2000). Interventions for people with alcohol use disorders and an intellectual disability: A review of the literature. Journal of Intellectual and Developmental Disability, Vol.25, No.2, pp135-146.

Anecdotal feedback from people working with this group report that they are rarely successful in meeting service entry criteria for drug and alcohol programs at interview. While the reasons for this are not clear, there is a view that these individuals present poorly on interview due to the exacerbating effects of co-morbid disability, mental health problems and substance abuse. They then often fail to demonstrate the continued motivation to engage in treatment that is required by services. For example, services often expect clients to make contact two or three times per week in order to maintain their place on the waiting list. Due to the nature of their disability, people with intellectual and cognitive disabilities are either unable to cope with waiting or have trouble remembering and planning. People with intellectual or cognitive disabilities have poor concepts of time. Their sense of time is very immediate, and they have extremely limited capacity to consider and plan for the future. They often rely on support in order to make phone calls to service providers on their behalf. This is often interpreted by drug and alcohol services as a lack of motivation.

Some drug and alcohol residential rehabilitation services also require potential clients to remain abstinent during the waiting period which can be a significant difficulty for this population. For example, some services require participants to be abstinent of all drugs, including prescribed medication. Many individuals in this group are reliant on prescribed medications for significant health issues, particularly those with co-morbid epilepsy or mental health problems. Therefore, abstaining from medication is contraindicated for this group. It is therefore essential that treatment services are amenable to working in an interdisciplinary way to ensure that all of the issues faced by these individuals can be addressed in an holistic manner.

Furthermore, due to the nature of their disability and the absence of support structures, this population is often at an increased risk of relapse unless directly supervised. Because people in this group are more likely to be abstinent during a period of incarceration, this affords a potential treatment entry opportunity for this group. However, very few services will assist people directly from prison and so such potential opportunities are missed. Finally, those who are selected for treatment in residential rehabilitation services often fail to comply with the rules governing their treatment program or to understand the various written materials that they are expected to read as part of treatment. Consequently they are often exited within a short period of time as a direct consequence of the interaction between the treatment and their disability.

The failure of mainstream drug and alcohol treatment services to be flexible to the particular needs of people with cognitive, intellectual and psychiatric disabilities increases the risk that these individuals come to the attention of the police and consequently the courts and correctional services, which struggle to appropriately address their needs.

An Integrated Care Model for Drug & Alcohol Treatment for People with Cognitive, intellectual and psychiatric Disabilities

The literature on effective drug and alcohol treatment for people with intellectual or cognitive disabilities, particularly those with co-morbid mental health problems identifies the following principles of good practice[2]:

- A detoxification programme supervised by health professionals. This is particularly vital for those who are socially isolated, homeless or needing medical or psychiatric care.
- Appropriate treatment goals such as abstinence rather than harm minimisation which is too abstract a concept for this group to comprehend.
- Social skills training to increase the person's capacity to deal with every day life.
- Communication skills training and problem solving techniques to reduce relapse.
- A residential service with no access to drugs or alcohol.

While we are not aware of any specialist drug and alcohol treatment program currently operating for this group in Australia, we are aware of a particular service organisation, Australian Community Support Organisation, that is including drug and alcohol treatment services as part of a comprehensive, integrated support model for people with cognitive and/or intellectual disabilities who have additional, complex needs.

A study by McGillivray and Moore states that "some individuals with intellectual disability may require intensive alcohol and other drug intervention programmes[3]. Again, these need to be specialised and rigorously evaluated in terms of efficacy with the target population (Christian & Poling, 1997). They also need to be made available to individuals at the onset of substance misuse, thus curtailing any escalation of damage associated with use. It is possible that early treatment may serve to minimise subsequent involvement in the criminal justice system". [4] This call for early treatment for these individuals is supported by a study by Taggart, McLaughlin, Quinn and Milligan who studied a group in Northern Ireland, the majority of who had been abusing substances for significant periods of time, with considerable deleterious effects, without having their substance abuse problem identified[5].

Recommendation

There is a significant body of anecdotal and research based evidence that the incidence of drug and alcohol use by people with cognitive and/or intellectual disabilities, and its impacts, is underestimated. There is also significant evidence that mainstream treatment responses are ineffective for this group.

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[2] Degenhardt (ibid)

[3] McGillivray, JA and Moore, MR (2001); Substance use by offenders with mild intellectual disability; Journal of Intellectual & Developmental Disability, Vol. 26, No. 4, pp. 297 – 310.

[4] Christian, LA and Poling, A (1997); Drug abuse in persons with mental retardation: a review.; American Journal on Mental Retardation, 102, 126 – 136 in McGillivray et. al. (ibid).

[5] Taggart, L; McLaughlin, D; Quinn, B & Milligan, V (2006); Journal of Intellectual Disability Research. Special Issue Mental Health and Intellectual Disability: XX. 50(8):588-597.

This submission recommends consideration of a targeted, integrated and therapeutic response for people with cognitive, intellectual and psychiatric disabilities that:

- Is specifically designed to ameliorate the interaction between cognitive and intellectual impairment (both with and without additional psychiatric illness) and substance use; and
- Provides an integrated care and support response that addresses the various and complex needs of people in this target group.